Assessing Needs and Resources for Children with Special Health Care Needs in New Hampshire

Executive Summary

October 2004

Special Medical Services Bureau
Office of Medicaid Business and Policy
NH Department of Health & Human Services

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Judith Bumbalo, Bureau Chief
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EXECUTIVE SUMMARY

Introduction

This report highlights the qualitative and quantitative methods and findings of a study undertaken by the New Hampshire Department of Health and Human Services, Special Medical Services Bureau. Specific attention is given to the implementation of a Delphi survey conducted during the winter and spring of 2004. The Delphi method is used for future forecasting and is an intense, iterative process by which stakeholders participate in survey completion and consensus building. It is expected that engagement and connection with the Delphi process will result in the priority ranking of issues, commitment of the participants, and continued engagement in working on identified priorities.

Background and Qualitative Process

Beginning in April 2001, the Special Projects Coordinator for Special Medical Services Bureau, New Hampshire Department of Health and Human Services, began a process to assess the concerns and opinions of NH stakeholders relative to children with special health care needs (CSHCN) and their families. Key informant interviews (n = 23) and focus group discussions (n = 14) were used to elicit responses to the following questions:

1. What trends do you think will continue to impact care/needed services for children with special health care needs and their families in the future?
2. What new knowledge will change and/or redefine the needs of children with special health care needs and their families in the future?
3. What current and projected societal trends (family, community issues) do you think will impact the needs of children with special health care needs and their families?
4. What do you see as the strengths and/or gaps/ deficiencies in current programs/services for this population of children/families?

A total of 110 professionals and family members representing over 40 different constituent groups participated in this process (Appendix A). Extensive written notes were recorded at the time of the interactions and transcribed immediately thereafter based on the discussion points. Initial data collection was completed in September 2001.
Based on preliminary analysis of the qualitative data, 88 emerging issues and 111 discrete concerns were identified. Further analysis of patterns and concepts produced nineteen (19) different themes that encompassed the issues identified by the participants.

Instrument Development

Beginning in January 2002 an extensive process began to translate the qualitative data into a written instrument in order to conduct a Delphi survey. Literature review was used to determine the criteria to construct Likert – type scales. Discrete items

were grouped based on the identified themes. Initially, respondents were asked to make judgments for 123 items based on four criteria and a seven-point scale from least important to most important.

Pilot testing of the initial instrument was conducted during early 2003 with 25 professional and family member volunteers. Based on feedback from respondents, the wording of individual items was further refined. The original 19 themes were grouped into 21 content areas. Finally, it was decided to reduce the complexity of the instrument by changing the Likert scale to five points and using only two criteria for judgment (i.e., potential of a program to impact the lives of CSHCN and their families; potential of a program for community and/or interagency collaboration to address issues). The final survey instrument was then developed (Appendix B).

Quantitative Process

Survey Instrument

Phase 1 Survey

During the first phase of the Delphi survey, the questionnaire developed from informant interviews and focus group discussion(s) was mailed to stakeholders who had participated in the initial qualitative stage. This instrument included 113 items within twenty-one topic areas. For each Item, respondents were asked to rate their perception of the *potential degree of impact on families* and *potential for collaboration* on a scale of 1 (low) to 5 (high). Surveys were mailed to 135 stakeholders and the response rate was 65%.

Phase 2 Survey

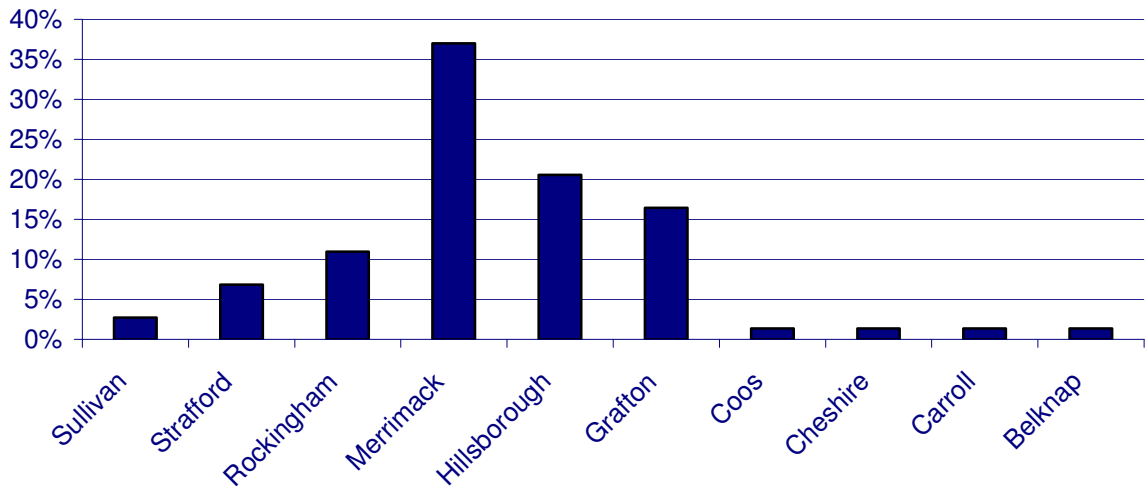
The second phase of the Delphi process was also a mailed survey that involved re-surveying first-round respondents (n = 88) using a modified *Phase 1* survey instrument. The most supported first-round survey items comprised the second-round survey instrument. Items not receiving the greatest support were excluded. Second phase respondents were provided not only their original score, but also the group mean score for each item. Respondents were asked to reconsider their original score and then to again rate their perception of the *potential degree of impact on families* and *collaboration potential* on a scale of 1 (low) to 5 (high). Eighty- three percent of surveys were returned. An additional three surveys were returned after data entry was complete and were not included in the final analysis.

Table 1. Data at a Glance

Instrument and Sample	*PHASE 1*	*PHASE 2*
Survey Instrument		
Number of Topic Areas	21	20
Number of Items	113	78
Sample		
Number of Mailed Surveys	135	88
Number of Returned Surveys	88	74
Response Rate	65%	83%
Affiliation	Professional – 77 Family – 11	Professional - 61 Family – 11 Did not answer- 2

Figure 1 shows the distribution of survey respondents by county. Counties with high survey participation rates are consistent with provider and population concentrations.

Figure 1. Distribution Of Delphi Survey Respondents by County



Analysis

Phase 1

Each Item received an aggregate mean and standard deviation score. An aggregate mean score of 3.9 or higher with a standard deviation less than or equal to 1 was selected to demark the score at which Items were deemed as receiving the greatest support. Items falling outside of these rules were viewed as least supported and excluded from the next survey phase.

Phase 2

Analysis for the second survey phase used aggregate means, mirroring the first phase. The broad topic areas and individual items for degree of impact on families and collaboration potential were rank ordered. Next the combined mean score (*impact on families + potential for collaboration*) was determined and ranked based on the top quartile to represent the items receiving the greatest support overall. Finally, the *impact on family* items were analyzed separately using stakeholder affiliation (professional versus family) and ranked based on the top items as reported by families.

Results

Table 2. shows that, in general, respondents rated the topic area of *Health Care Coordination* as having the greatest potential impact on the family, followed by the areas of *Mental Health Issues, Child Care and Respite Care, Increased School Intervention, and Transition Services.*

N.B. Color coding in all tables reflects topic areas.

Table 2. Topic Areas with the Greatest Potential for Impact on Families

RANK	TOPIC AREA
1	HEALTH CARE COORDINATION
2	MENTAL HEALTH
3	CHILD CARE and RESPITE
4	SCHOOLS
5	TRANSITION

Respondents also indicated that *Health Care Coordination* has the greatest potential for collaboration, followed by the area of *Educational Needs of Parents, Home-Based Services, Special Needs Diagnosis* and *Diagnostic Options* (Table 3.)

Table 3. Topic Areas with the Greatest Potential for Collaboration

RANK	TOPIC AREA
1	HEALTH CARE COORDINATION
2	EDUCATIONAL NEEDS OF PARENTS
3	HOME-BASED SERVICES
4	SPECIAL NEEDS DIAGNOSES
5	DIAGNOSTIC OPTIONS for CSHCN

Table 4 shows the top 10 items deemed as having potential for the greatest degree of impact on families. These items are associated with five different topic areas. Items related to Child Care and Respite and Health Care Coordination each represent one – third of the ten highest rankings.

Table 4. Top 10 Items Having the Greatest Potential for Impact on Families

RANK	DEGREE OF IMPACT ON FAMILIES
1	Respite care for behaviorally and medically complex children
2	Lack of mental health services / professionals skilled in pediatric / family-based treatment
3	Home-based services for children with medical/behavioral needs
4	Coordination at all points of transition (e.g., preschool, middle to HS, youth to adult)
5	Increasing demand for child care options for families with young children with behavioral problems
6	Adequate Medicaid reimbursement for providers
7	Need for intra-agency cooperation/collaboration
8	Funding of schools to meet the needs of CSHCN to avoid rationing of special education and related services
9	Case coordination for the most involved, medically complex children
10	Need for SSI and other funding after 18 years of age

Table 5 illustrates the top 10 items deemed as having the greatest potential for collaboration. Of these, fifty percent fall under the *Health Care Coordination* topic area. The remaining items are derived from the *Lack of Capacity, Educational Needs of Parents*, and *Transition Services* topic areas.

Table 5. Top 10 Items with the Greatest Potential for Collaboration

RANK	POTENTIAL FOR COLLABORATION
1	Need for intra-agency cooperation/collaboration
2	Case coordination for the most involved, medically complex children
3	Continuing education/technical assistance for providers
4	The health/medical needs of adolescents and CSHCN in transition (age 14-21)
5	Training for all staff in family-centered principles of care
6	Coordination at all points of transition (e.g., preschool, middle to HS, youth to adult)
7	Parent skill training in behavior and health
8	Educational materials for parents that are clear and pragmatic
9	Support for care coordinators in the community
10	Care coordination in primary care offices

In order to narrow the focus to specific issues for further discussion and future priorities, the next analysis combined the mean scores for degree of impact on families and potential for collaboration to indicate most overall support. Table 6. shows the first quartile, in rank order, of the 18 items with the greatest combined score, hence, the most overall support.

Table 6. Top 25% Most Supported Items Using the Combined Impact and Collaboration Scores

RANK	COMBINED IMPACT AND COLLABORATION ITEMS	TOPIC AREA
1	Need for interagency cooperation/collaboration	Health Care Coordination
2	Respite care for behaviorally and medically complex children	Child Care and Respite
3	Case coordination for the most involved, medically complex children	Health Care Coordination
4	Coordination at all points of transition (e.g., preschool, middle to HS, youth to adult)	Health Care Coordination
5	The health/medical needs of adolescents and CSHCN in transition (age 14-21)	Transition
6	Home-based services for children with medical and behavioral needs	Child Care and Respite
7	Increasing demand for child care options for families with young children with behavioral problems	Child Care and Respite
8	Care coordination in primary care offices	Health Care Coordination
9	Funding of schools to meet the needs of CSHCN to avoid rationing of special education and related services	Schools
10	Need for family support and counseling	Mental Health
11	Lack of mental health services / professionals skilled in pediatric / family-based treatment	Mental Health
12	Need for interagency partnerships / collaboration between health and educational communities	Schools
13	Specific training for professionals/paraprofessionals to provide care in home settings	Home-Based Services
14	Need for prepared/expert professionals	Lack of Capacity
15	Provision of adult health care for the special needs population	Transition
16	Increasing number of children with significant medical problems who live at home	Home-Based Services
17	Early diagnosis and treatment of mental health problems	Mental Health
18	Need for home – school collaboration and coordination	Schools

Because family members of CSHCN were under represented in the final survey, it was not appropriate to categorize respondents for statistical comparison. Nonetheless, it is critically important to have an idea of family members' perceptions regarding programs they view as having the most potential impact on their lives. Table 7 illustrates the top 10 items that received the highest mean scores from family – member respondents. Items one through eight reflect the overall survey results; however, items nine and ten (related to public funding and health care cost) are unique to the priority issues identified by the family – member respondents.

Table 7. Families' Perceptions of Items Having the Greatest Impact on Families

1	**Respite care for behaviorally and medically complex children**	**Child Care and Respite**
2	**Provision of adult health care for the special needs population**	**Transition**
3	**Need for interagency cooperation/collaboration**	**Health Care Coordination**
4	**Need for SSI and other funding after 18 years of age**	**Transition**
5	**Lack of mental health services / professionals skilled in pediatric / family-based treatment**	**Mental Health**
6	**Increasing demand for child care options for families with young children with behavioral problems**	**Child Care and Respite**
7	**Home-based services for children with medical and behavioral needs**	**Child Care and Respite**
8	**Need for family support and counseling**	**Mental Health**
9	**Demand for blending / coordination of funding sources / funding flexibility**	**Public Funding**
10	**Demand for coverage for durable medical equipment and non-pharmaceutical products**	**Health Care Cost**

Study Limitations

Several limitations of this work have been identified:

- Although identified as being very important and valuable stakeholders, and included in the original survey mailings, family members are under represented in the Delphi survey. An additional needs assessment will be specifically targeted at families.
- In the attempt to be all-inclusive and sensitive to stakeholder input, and reflecting the desire to have the final survey instrument mirror the breadth and complexity of the original qualitative process, survey completion time was labor intensive for respondents. This may have influenced participation and reliability.

- Although not strictly a limitation, it should be acknowledged that the Delphi survey asked respondents to rate the perceived impact of a single item, not rank its importance relative to other items.
- Although a strict ranking process may have provided additional insights, the methods used here provide the relative importance or value of an item ranked by aggregate means. It should be noted that all items used in the survey were identified as important by participating stakeholders.

Summary and Conclusions

Using an extensive qualitative and quantitative process, stakeholders in New Hampshire have identified 18 priority issues of concern in relation to CSHCN. If programs addressing these issues were developed and/or further refined, survey participants believe that there is potential to significantly impact the lives of CSHCN and their families. Furthermore, respondents have indicated that programs related to these concerns have significant potential for community and/or interagency collaboration.

In conclusion:

- The mandate to improve interagency collaboration is clear.
- The expressed need to address mental health services for this population is consistent with many previous findings and a specific priority for family members.
- Programs addressing care coordination in a variety of settings are also viewed as having priority.
- The finding that over five of the items ranked in the first quartile are related to home-based services and respite or childcare needs speaks loudly to perceived gaps in our current service delivery system.
- There is consensus that health care transition for adolescents must receive attention.
- Three of the most highly ranked items call for renewed efforts to coordinate services between home, school and the medical community.
- The results of the survey indicate that we must seriously consider the concerns of families regarding public funding and specific health care costs for CSHCN.
- The ongoing need for expert professionals in the field must be addressed.

The challenges facing professionals, families and communities in the next decade are clear. It is time to get on with the work of assuring the health and quality of life for every child with special needs in New Hampshire.

APPENDICES

Appendix A: **Stakeholders/Invited Participants**

Appendix B: **Original Survey Instrument**

APPENDIX A

STAKEHOLDERS/INVITED PARTICIPANTS

Anthem Blue Cross/Blue Shield Care Managers

Capital Region Family Health Center

Child Health Services Manchester

Children's Alliance of New Hampshire

Community Health and Hospice Laconia

Concord Regional Visiting Nurse Association

Council on Children and Adolescents with Chronic Health Conditions

Crotched Mountain Rehabilitation Center

Dartmouth-Hitchcock Medical Center

- Center for Medical Home Improvement
- Child Development and Genetics
- Department of Pediatrics
- Hood Center for Families and Children
- Partnerships for Enhanced Medical Care
- STAR Program (Steps Toward Adult Responsibility)

Disability Rights Center

Easter Seals of New Hampshire

Exeter Pediatrics

Granite State Independent Living

Infant Mental Health Association

Institute on Disability

- Project Connection
- Project Jump Start

Interim HealthCare

Lamphrey Health Center

Monadnock Pediatrics

National Alliance for the Mentally Ill (NAMI) New Hampshire

New Hampshire Child Development Network

APPENDIX A continued

New Hampshire Department of Education

- Bureau of Special Education

New Hampshire Department of Health and Human Services

- Bureau of Maternal and Child Health
  - Healthy Child Care New Hampshire
- Department of Children, Youth and Families
  - Foster Care Programs
- Department of Medicaid Business and Policy
  - Special Medical Services Bureau
    - Special Medical Services Bureau Family Advisory Board
- Division of Behavioral Health
  - Project Care New Hampshire
- Division of Developmental Services
  - Area Agencies
  - Early Supports and Services
  - MICE (Multi-sensory Intervention through Consultation and Education)
  - Traumatic Brain Injury Program: Project Response

New Hampshire Developmental Disabilities Council

New Hampshire Family Voices

New Hampshire Federation for Families

Parent Information Center

Pediatric Physical Therapy Inc.

Pediatric Society of New Hampshire

Preschool Technical Assistance Network (PTAN)

Richie McFarland Children's Center

SERESC (Southeastern Regional Educational Service Center)

APPENDIX B

DEFINITION of Children with Special Health Care Needs

The federal Maternal and Child Health Bureau defines children with special health care needs (CSHCN) as those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.[1]

DIRECTIONS

SURVEY QUESTIONS

1. If programs could be developed to address some of the issues affecting CSHCN and their families, what do you think the **degree of impact** would be, for each issue?

2. What might be the **potential for collaboration** among interested stakeholders?

COMPLETING THE SURVEY

1. Please rank the **degree of impact** for each item listed in the survey, on a scale of 1-to-5.

One (1) is the lowest degree of positive, significant impact and 5 is the highest degree of positive, significant impact.

2. Also rank the **potential for the development of community and/or interagency collaboration**, for each issue.

Use the same scale, with 1 being the lowest potential and 5 being the highest potential.

PLEASE

DO NOT LEAVE ANY ITEM BLANK
AND SELECT ONLY ONE WHOLE NUMBER FOR EACH ITEM.

This is important for the automated data analysis process.

[1] McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102:137-140.

A. If programs could be developed to address any of the following **ACCESS TO CARE** issues, what degree of impact do you think each would have on the lives of children with special health care needs (CSHCN) and their families? What do you think the potential is for community and/or interagency collaboration to address these issues?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
A-1	Service and health status disparities based on geographic region (esp. rural NH)	1 2 3 4 5	1 2 3 4 5
A-2	Isolation of families leading to delay in treatment and increased self-treatment	1 2 3 4 5	1 2 3 4 5
A-3	Lack of access to adequate dental care	1 2 3 4 5	1 2 3 4 5
A-4	Lack of transportation options to access care; cost of transportation	1 2 3 4 5	1 2 3 4 5
A-5	Need for a directory of services	1 2 3 4 5	1 2 3 4 5
A-6	Limited access to technology and/or databases	1 2 3 4 5	1 2 3 4 5

B. Health services to CSHCN have been affected by the **LACK OF CAPACITY** in the current system, including a lack of professionals and a lack of education and expertise about special needs populations. Please rank the degree of impact upon CSHCN and their families if programs could be developed to address these issues. Also rank the potential for community and/or interagency collaboration to address these issues.

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
B-1	Need for more Certified Nursing Assistants (CNA)	1 2 3 4 5	1 2 3 4 5
B-2	Need for prepared/expert professionals	1 2 3 4 5	1 2 3 4 5
B-3	Continuing education/technical assistance for providers	1 2 3 4 5	1 2 3 4 5
B-4	Training for all staff in family-centered principles of care	1 2 3 4 5	1 2 3 4 5
B-5	Need for experts in endocrinology, gastroenterology, metabolic disorders	1 2 3 4 5	1 2 3 4 5
B-6	Mechanisms to influence pediatric residency training	1 2 3 4 5	1 2 3 4 5

C. Changes in family demographics have created a new group of needs in NH. If initiatives could be developed to address the issues of **FAMILY DEMOGRAPHICS AND SUPPORT** listed below, what degree of impact do you think this would have on CSHCN and their families? What is the potential for community and/or interagency collaboration around each issue?

	PROGRAMS TO ADDRESS	**DEGREE OF IMPACT**	**COLLABORATION POTENTIAL**
C-1	Coordination of resources/capacity across geographic areas	1 2 3 4 5	1 2 3 4 5
C-2	Increasing number of children in poverty in NH	1 2 3 4 5	1 2 3 4 5
C-3	Lack of services for working poor	1 2 3 4 5	1 2 3 4 5
C-4	Need for outreach strategies to bring underserved into the system of care	1 2 3 4 5	1 2 3 4 5
C-5	Social support for families due to fewer nuclear and extended family constellations	1 2 3 4 5	1 2 3 4 5
C-6	Services for children being raised by grandparents	1 2 3 4 5	1 2 3 4 5
C-7	Services for homeless families	1 2 3 4 5	1 2 3 4 5
C-8	Increasing number of older parents in the caretaker role for CSHCN	1 2 3 4 5	1 2 3 4 5

D. Please rank the degree of impact programs to address the following **CHILD CARE and RESPITE** options would have on CSHCN and their families. What is the community and/or interagency collaboration potential to address these issues?

	PROGRAMS TO ADDRESS	**DEGREE OF IMPACT**	**COLLABORATION POTENTIAL**
D-1	Respite care for behaviorally and medically complex children	1 2 3 4 5	1 2 3 4 5
D-2	Home-based services for children with medical and behavioral needs	1 2 3 4 5	1 2 3 4 5
D-3	Need for group care/congregate care as long term living options	1 2 3 4 5	1 2 3 4 5
D-4	Increasing demand for child care options for families with young children with behavioral problems	1 2 3 4 5	1 2 3 4 5

E. If initiatives could be developed to address the following **NEW TREATMENT OPTIONS** what would be the degree of impact on CSHCN and their families? What is the potential for community and/or interagency collaborative programs for these issues?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
E-1	Increased use of pharmacology and the need for individualized evaluation and management	1 2 3 4 5	1 2 3 4 5
E-2	Information regarding allergies (e.g., food, latex) and associated treatments (e.g., dietary)	1 2 3 4 5	1 2 3 4 5
E-3	Increasing knowledge of brain function/chemistry with associated new treatments/interventions	1 2 3 4 5	1 2 3 4 5
E-4	Use of biomechanical engineering to provide treatment (e.g. robotics, specialized mobility devices)	1 2 3 4 5	1 2 3 4 5
E-5	Increasing knowledge of metabolism and nutrition leading to new treatments/service needs	1 2 3 4 5	1 2 3 4 5
E-6	Increased use of cochlear implants requiring both individual and family treatment/education	1 2 3 4 5	1 2 3 4 5

F. HOME-BASED SERVICES are required by some CSHCN. Please rank the degree of impact on CSHCN and their families if the following issues were addressed through new initiatives. What is the potential for community and/or interagency collaboration?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
F-1	Increasing number of children with significant medical problems who live at home	1 2 3 4 5	1 2 3 4 5
F-2	Educational services and care in the home setting	1 2 3 4 5	1 2 3 4 5
F-3	Specific training for professionals/paraprofessionals to provide care in home settings	1 2 3 4 5	1 2 3 4 5
F-4	Parents forced to leave employment to provide in-home care for CSHCN	1 2 3 4 5	1 2 3 4 5

G. What degree of impact would programs to address the **EDUCATIONAL NEEDS OF PARENTS** have on CSHCN and their families? What is the potential for community and/or interagency collaboration to develop such programs?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
G-1	Parent skill training in behavior and health	1 2 3 4 5	1 2 3 4 5
G-2	Preparation of parents for leadership roles	1 2 3 4 5	1 2 3 4 5
G-3	Assisting parents with technology used with CSHCN (e.g., hardware and software possibilities)	1 2 3 4 5	1 2 3 4 5
G-4	Parent-to-parent helping models that reimburse the "teacher"	1 2 3 4 5	1 2 3 4 5
G-5	Educational materials for parents that are clear and pragmatic	1 2 3 4 5	1 2 3 4 5

H. If initiatives could be developed for the following **HEALTH CARE COORDINATION** issues, what degree of impact would these have on CSHCN and their families? To what degree do you think there is a potential for interagency and/ or community collaboration in these areas?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
H-1	Support for care coordinators in the community	1 2 3 4 5	1 2 3 4 5
H-2	Care coordination in primary care offices	1 2 3 4 5	1 2 3 4 5
H-3	Case coordination for the most involved, medically complex children	1 2 3 4 5	1 2 3 4 5
H-4	Integration of care between primary and tertiary care settings	1 2 3 4 5	1 2 3 4 5
H-5	Coordination at all points of transition (e.g., preschool, middle to HS, youth to adult)	1 2 3 4 5	1 2 3 4 5
H-6	Need for intra-agency cooperation/collaboration	1 2 3 4 5	1 2 3 4 5

I. Children born with conditions such as cystic fibrosis and spina bifida are surviving into adulthood due to improvements in treatment, and chronic conditions such as asthma, diabetes and mental illness are increasing. What would be the degree of impact on Youth with Special Health Care Needs (YSHCN) and their families if services were developed to help them with the following **TRANSITION** issues? What is the potential for collaboration on these issues?

	PROGRAMS TO ADDRESS	**DEGREE OF IMPACT**	**COLLABORATION POTENTIAL**
I-1	The health/medical needs of adolescents and CSHCN in transition (age 14-21)	1 2 3 4 5	1 2 3 4 5
I-2	Provision of adult health care for the special needs population	1 2 3 4 5	1 2 3 4 5
I- 3	Provider education regarding the developmental issues of youth and young adults with special health care needs	1 2 3 4 5	1 2 3 4 5
I- 4	Self-advocacy skills for youths with special health care needs	1 2 3 4 5	1 2 3 4 5
I- 5	Adequate funding for inclusion / self determination models of care	1 2 3 4 5	1 2 3 4 5
I- 6	Need for SSI and other funding after 18 years of age	1 2 3 4 5	1 2 3 4 5

J. What degree of impact would initiatives to address the following **MULTICULTURAL ISSUES** have on CSHCN and their families? What is the potential for collaboration within the community and/or interagency to develop programs?

	PROGRAMS TO ADDRESS	**DEGREE OF IMPACT**	**COLLABORATION POTENTIAL**
J-1	Need for cultural competence among providers and health care organizations	1 2 3 4 5	1 2 3 4 5
J-2	Lack of training focusing on multicultural issues	1 2 3 4 5	1 2 3 4 5
J-3	Increasing need to serve immigrant populations	1 2 3 4 5	1 2 3 4 5
J-4	Need for interpreters in health care settings	1 2 3 4 5	1 2 3 4 5
J-5	Differing beliefs and values re: self sufficiency and using public services	1 2 3 4 5	1 2 3 4 5

K. Health and disease information is readily available from multiple resources, including the Internet. If initiatives were developed to address this **KNOWLEDGE EXPLOSION** what degree of impact might there be on CSHCN and their families? What is the potential for community and/or interagency collaboration on these issues?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
K-1	Increased need for parent - professional dialogue due to increasingly sophisticated consumers of care (educated via the Internet and other sources)	1 2 3 4 5	1 2 3 4 5
K-2	Need to assist families and professionals to evaluate and process new knowledge	1 2 3 4 5	1 2 3 4 5
K-3	Use of the Internet for diagnosis, counseling and consultation	1 2 3 4 5	1 2 3 4 5

L. SCHOOLS provide necessary treatment, care and related services to CSHCN. What degree of impact would initiatives to address the following issues have on CSHCN and their families? What is the potential for community and/or interagency collaboration?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
L-1	Demand for more complex nursing care in school settings	1 2 3 4 5	1 2 3 4 5
L-2	Support & education for school nurses	1 2 3 4 5	1 2 3 4 5
L-3	Funding of schools to meet the needs of CSHCN to avoid rationing of special education and related services	1 2 3 4 5	1 2 3 4 5
L-4	Need for after school and recreational activities for CSHCN	1 2 3 4 5	1 2 3 4 5
L-5	Need for interagency partnerships / collaboration between health and educational communities	1 2 3 4 5	1 2 3 4 5
L-6	Need for home – school collaboration and coordination	1 2 3 4 5	1 2 3 4 5

M. New knowledge has led to new **DIAGNOSTIC OPTIONS** for CSHCN. What would be the degree of impact on CSHCN and their families if services to address these issues were developed? What is the potential for community and/or interagency collaboration?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
M-1	Increased recognition of co-morbidity and dual diagnoses	1 2 3 4 5	1 2 3 4 5
M-2	Role of the environment in the etiology of health and developmental problems	1 2 3 4 5	1 2 3 4 5
M-3	Focus on prevention of chronic illness in children; (e.g., folic acid & spina bifida, asthma protocols)	1 2 3 4 5	1 2 3 4 5
M-4	Newborn hearing screening leading to earlier diagnosis and need for intervention (under 1 year)	1 2 3 4 5	1 2 3 4 5
M-5	Genetic counseling/treatment (new knowledge)	1 2 3 4 5	1 2 3 4 5

N. If initiatives could be developed to address the following needs of **VULNERABLE POPULATIONS**, what would be the degree of impact on CSHCN and their families? What is the potential for community and/or interagency collaboration?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
N-1	Increased number of CSHCN in foster care	1 2 3 4 5	1 2 3 4 5
N-2	Need for adoption/ permanency for CSHCN in out-of-home placement	1 2 3 4 5	1 2 3 4 5
N-3	Medical/health needs of emotionally disturbed children	1 2 3 4 5	1 2 3 4 5
N-4	Need for services for youth with special needs in the juvenile justice system (e.g., evaluation, medical services, mental health services)	1 2 3 4 5	1 2 3 4 5
N-5	Transitional support for teens leaving the foster care system or detention (e.g., mentors, housing, health care)	1 2 3 4 5	1 2 3 4 5

O. There is an increasing population of children with **SPECIAL NEEDS DIAGNOSES.** Please rank the degree of impact for CSHCN and their families if programs could be developed to address the following areas. What is the potential for community and/or interagency collaboration?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
O-1	The increasing survival of low birth weight babies with associated biological, cognitive, developmental and behavioral problems	1 2 3 4 5	1 2 3 4 5
O-2	Growing population of children with complex medical needs	1 2 3 4 5	1 2 3 4 5
O-3	Increasing longevity of CSHCN population associated with improved treatment (e.g., cancer, cardiac)	1 2 3 4 5	1 2 3 4 5

P. If initiatives could be developed to address the following **MENTAL HEALTH** issues, what degree of impact do you think each would have on the lives of CSHCN and their families? What is the potential for community and/or interagency collaboration?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
P-1	Early diagnosis and treatment of mental/emotional/ behavioral disorders in children	1 2 3 4 5	1 2 3 4 5
P-2	Need for family support and counseling	1 2 3 4 5	1 2 3 4 5
P-3	Lack of mental health services / professionals skilled in pediatric / family-based treatment	1 2 3 4 5	1 2 3 4 5
P-4	Need for early identification of infants and families at risk (e.g., addiction / domestic abuse)	1 2 3 4 5	1 2 3 4 5
P-5	Need for support groups for families	1 2 3 4 5	1 2 3 4 5
P-6	Need for information on how to access mental health services	1 2 3 4 5	1 2 3 4 5

Q. The delivery of quality services is the outcome of good **SYSTEMS PLANNING.** What degree of impact would such planning have on the following areas, if initiatives could be developed to address them? What is the potential for community and/or interagency collaboration for these areas?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
Q-1	Emphasis on evidence – based practice	1 2 3 4 5	1 2 3 4 5
Q-2	Adequate data systems to support care for CSHCN and families	1 2 3 4 5	1 2 3 4 5
Q-3	Demand for outcomes and accountability in healthcare and other service arenas	1 2 3 4 5	1 2 3 4 5
Q4	Inconsistency / differences in quality across programs, services	1 2 3 4 5	1 2 3 4 5
Q-5	Incorporation of a Continuous Quality Improvement process into state-funded agencies	1 2 3 4 5	1 2 3 4 5

R. If initiatives were developed to address the following **ETHICAL ISSUES,** what degree of impact would each have on the lives of CSHCN and their families? What is the potential for community and/or interagency collaboration?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
R-1	Complex ethical dilemmas associated with priorities, cost of care, available resources, expanding scientific info	1 2 3 4 5	1 2 3 4 5
R2	Possibility for genetic discrimination associated with familial syndromes	1 2 3 4 5	1 2 3 4 5
R3	Reimbursement for services based on the predicted natural history of a “diagnosis” rather than that of an individual child	1 2 3 4 5	1 2 3 4 5
R-4	Different expectations regarding care/treatment from consumers, medical professionals, managed care organizations	1 2 3 4 5	1 2 3 4 5

S. If initiatives could be developed to address issues of **PUBLIC FUNDING,** what do you think would be the degree of impact for CSHCN and their families? What is the potential for community and/or interagency collaboration?

PROGRAMS TO ADDRESS		DEGREE OF IMPACT	COLLABORATION POTENTIAL
S-1	Increase in the demand for Medicaid	1 2 3 4 5	1 2 3 4 5
S-2	Need for Medicaid restructuring	1 2 3 4 5	1 2 3 4 5
S-3	Potential for the rationing of services	1 2 3 4 5	1 2 3 4 5
S-4	Need for follow-up with families who are denied SSI or HC-CSD (Katie Beckett)	1 2 3 4 5	1 2 3 4 5
S-5	Adequate Medicaid reimbursement for providers	1 2 3 4 5	1 2 3 4 5
S6	Demand for blending / coordination of funding sources / funding flexibility	1 2 3 4 5	1 2 3 4 5
S-7	Increasing focus on set-aside, “carve-out” programs	1 2 3 4 5	1 2 3 4 5
S-8	Teaching families how to navigate/negotiate a complex and difficult service system	1 2 3 4 5	1 2 3 4 5
S-9	Need for new coding systems associated with new diagnosis, to insure payment	1 2 3 4 5	1 2 3 4 5

T. If initiatives could be developed to address the following issues related to **VALUES,** what degree of impact might this have on CSHCN and their families? What is the potential for community and/or interagency collaboration?

PROGRAMS TO ADDRESS		DEGREE OF IMPACT	COLLABORATION POTENTIAL
T-1	Increasing tension between inclusion versus exclusion of the child with disabilities in community settings.	1 2 3 4 5	1 2 3 4 5
T-2	Responsibilities of the larger community for the needs of CSHCN	1 2 3 4 5	1 2 3 4 5
T-3	Educating politicians about the changing needs of constituents/families of CSHCN	1 2 3 4 5	1 2 3 4 5

U. HEALTH CARE COST remains a major barrier to access. Health insurance is not readily available to all segments of the NH population. If programs could be developed to address the following issues what degree of impact would there be for CSHCN and their families? What is the potential for community and/or interagency collaboration?

	PROGRAMS TO ADDRESS	DEGREE OF IMPACT	COLLABORATION POTENTIAL
U-1	Increasing difficulty in obtaining adequate insurance coverage for CSHCN	1 2 3 4 5	1 2 3 4 5
U-2	Demand for coverage for durable medical equipment and non-pharmaceutical products	1 2 3 4 5	1 2 3 4 5
U-3	Frequent changes in insurance (e.g., with uncertain job market)	1 2 3 4 5	1 2 3 4 5
U-4	Limits imposed by the use of "health accounts" and the potential for medical needs of CSHCN not being covered	1 2 3 4 5	1 2 3 4 5
U-5	Co-pays, items not covered by insurance, out of pocket expenses	1 2 3 4 5	1 2 3 4 5
U-6	Increasing number of working poor not eligible for services	1 2 3 4 5	1 2 3 4 5
U-7	Difficulties/ demands associated with specialty referrals; "out of network" referrals	1 2 3 4 5	1 2 3 4 5
U-8	Payment for alternative / complementary treatment, (e.g., medications, nutritional, acupuncture)	1 2 3 4 5	1 2 3 4 5

End of Survey

Please review to be sure that the survey was completed by responding to <u>all</u> items in <u>both</u> columns.